

Living with hope and cystic fibrosis

By **KATHERINE LOW**

May 25, 2010 2:00 AM

For many young people, May is a time for graduation and planning for the future. They look forward to getting out into the real world, their first job, meeting their life mate. These days especially, they are likely to worry about money, career, expectations for success.

As I approach my own graduation from the Suffolk University program at Cape Cod Community College, I have a different perspective.

I was born with cystic fibrosis. I was baptized right away, not weighed and measured, because the doctors weren't sure I would survive. As I was rushed down the hospital corridor to intensive care, my parents were very frightened. I grew up with constant medical treatment and the reality of a limited life expectancy always hanging over my head.

As you might imagine, this has been a huge burden for my family and me. But you might be surprised to hear that I also consider it a blessing.

Every birthday is truly a time for celebration. Most people worry about aging, but I yearn to experience graying hair and laugh lines circling my mouth. I don't expect them. I can't.

But I do live by hope. I hope to see smiles of children that I can call mine, and hope to feed my grandchildren chocolate chip cookies around a hearth I can call my own. I hope that one day someone with CF won't have to weigh the risks of having their own children die of CF, or they themselves dying when their children are young.

And then there are things I don't even have to hope for, because I already have them: knowing I am loved and cherished by my family and friends, including my wonderful boyfriend who makes me feel like the world is pure.

I spent the last semester interning at Hospice & Palliative Care of Cape Cod, learning about the resources available for the many patients and families coping with serious illness. I saw that everyone has a story to tell. At every hospice event I went to, someone came up to me and shared their experience dealing with loss. I saw how their perspective on life and death gave them a special appreciation that echoed some of mine.

I believe that the most important things in life are the relationships we nurture. Death is uncontrollable; it can touch anyone at any time, without notice. I know that. There is not one day that I am not appreciating being alive.

I urge you to go out of your element and experience something or someone that makes you think differently. Life was not designed to be easy, but it is worthwhile. I live for experiences, for picnics with good food and wine, and moments when I don't want to go home.

People live their whole lives working; only at the end might they consider what gave their life meaning. Every day ask yourself: What are your goals for your life? What is important to you? I have been blessed because I know the importance of figuring out life's meaning and then living accordingly.

I am not so different from you; I don't look like a sick person. I could be sitting next to you at your office, or waiting on your family at dinner. Everyone is similar, with goals, fears, hopes and a lot of stress. We are all special. Including you!

Life is a terminal illness for all of us. It might last 10 more years, or 30; you never know. I have had several friends die from cystic fibrosis in the past few years and every time I wonder: why not me? Why am I stuck in this paradox of being sick, yet outliving others? Why do I feel like I'm the only one of us left? No one who is loved ever truly dies. So long as their memories are alive, stories can be told and passed on, keeping their spirit with us.

I have had the pleasure of knowing amazing people who never complained, had great senses of humor and took every day as a time for happiness — regret just wasn't a word in their vocabulary. They lived too briefly, but so unconditionally and with such passion that thinking of them makes me cry. I miss being close to others who have the same burdens. Every time I do something special, I think of them, and carry them with me as I continue on my life's journey.

This month I am off to Italy to study photojournalism with Suffolk University, and then to Puerto Rico to celebrate the joys of my relationship. Afterward I will return home to Cape Cod, to fulfill my dreams of a home and family, much like many others graduating soon. May we all find the hope and joys in each of our unique lives, for whatever time we each may have.

Katherine Low lives in Sandwich.

Copyright © Cape Cod Media Group, a division of Ottaway Newspapers, Inc. All Rights Reserved.